

Kleederman SB 368

Proposed Bill No. 368 Public Hearing on March 8, 2013

I lived in Middletown, CT for 7 years, first as a student at Wesleyan and then as a teacher at a local, private day school. I used to be a very active person. I loved to hike and ski, taught Zumba, ran, lifted weights and lived the life of an active, 25 year old. I loved physical activity and thrived on it. Between May and September of 2012, I noticed that I had flu-like symptoms about once a month. I began to feel weak during physical activity. I also had bladder pain and regular headaches. In the fall of 2012, my flu-like symptoms were worse. I felt nauseous, and had exhaustion like I had never experienced before in my life. At this time, I had a Western Blot Lyme test which had a positive result. I then began oral antibiotics for 2 months, which I struggled to tolerate due the side effects. During this time, my symptoms expanded to include terrible joint pain, light sensitivity, night sweats, and exhaustion even from very little activity. I got no relief from the oral antibiotics.

My life had changed as I could not work a full time job, could not walk distances without pain and discomfort, had difficulty sleeping through the night, and had visual focusing issues. I had terrible joint pain, bladder pain, and had no energy to complete life's daily tasks. After two months of oral antibiotics, I needed to seek out different medical treatment and find a physician who would look beyond the protocol accepted by most doctors.

I reached out to the family of a former student of mine in CT who I knew had bravely and unwaveringly sought out treatment and care for their daughter who was also diagnosed with Lyme and co-infections several years ago. I was fortunate to see their doctor in New York City, a doctor who evaluated my situation carefully and listened to my individual host of symptoms. I have been on IV antibiotics for three months and a number of other medications to treat co-infections also caused by the tick. My insurance covers none of my treatment because my test results don't show the particular bands and evidence that they require. I am slowly making progress in healing from this complex disease. Although I am still unable to work full-time, I am showing slow signs of improvement. In the process of finding answers for myself, I have been overwhelmed by other people's testimonies and experiences of misdiagnosis, abbreviated treatment, and incredible hardship.

I hope that my testimony, along with others, will help to raise awareness and bring about positive change in terms of how Lyme disease and co-infections are understood, diagnosed, and treated.

Sincerely,
Julia Kleederman